# **UNION COUNTY**

# Cancer Control and Prevention Capacity and Needs Assessment Report Summary

December 2004

# **Funds and Support Provided By**



New Jersey Department of Health and Senior Services Center for Cancer Initiatives The Office of Cancer Control and Prevention

#### **Notices:**

Medicine is an ever-changing science. As new research and data broaden our knowledge, conclusions may change. The authors and reviewers have endeavored to check the sources of information and to utilize sources believed to be the most reliable in an effort to provide information that is as complete as possible at the time of submission and generally in accord with appropriate standards. However, in view of the possibility of human error or changes in medical science, this work cannot be warranted as being complete and accurate in every respect. Readers are encouraged to confirm the information contained herein with other sources. Information concerning some of the sources of data, rationale for its utilization, acknowledgements of specific parties contributing to these efforts, as well as links to cancer-related information may be found at <a href="https://www.umdnj.edu/evalcweb/">www.umdnj.edu/evalcweb/</a>.

This county-level Report Summary summarizes the larger county report, which is a baseline evaluation of this county, performed as part of the Capacity and Needs Assessment initiative of the New Jersey Comprehensive Cancer Control Plan (<a href="www.state.nj.us/health/ccp/ccc\_plan.htm">www.state.nj.us/health/ccp/ccc\_plan.htm</a>), under the direction of the New Jersey Department of Health and Senior Services (NJDHSS) Office of Cancer Control and Prevention (OCCP) (<a href="www.state.nj.us/health/ccp/">www.state.nj.us/health/ccp/</a>), the University of Medicine and Dentistry of New Jersey (UMDNJ) (<a href="www.umdnj.edu/evalcweb/">www.umdnj.edu/evalcweb/</a>), and the Evaluation Committee of the Governor's Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey (Task Force Chair: Arnold Baskies, MD; Evaluation Committee Chair: Stanley H. Weiss, MD).

Comments may be sent to the first author of the Report Summary, Mr. William Bullock, at <a href="mailto:bbullock20@aol.com">bbullock20@aol.com</a>. Copies of any comments should also be sent to both: Ms. Knight <a href="mailto:peg.knight@doh.state.nj.us">peg.knight@doh.state.nj.us</a> and Dr. Weiss <a href="mailto:weiss@umdnj.edu">weiss@umdnj.edu</a>.

All material in this Report Summary is hereby entered into the public domain, and may be reprinted without permission; however, in keeping with general standards of scholarly integrity, appropriate citation is requested.

# **Suggested citation** for this Report Summary:

Bullock W, Bock RP, Akinosho P. Union County Cancer Capacity and Needs Assessment Report Summary, December 2004. In: *New Jersey Statewide County-based Cancer Capacity and Needs Assessment Initiative*, 2003–2004 Report Summaries, Editors: Stanley H. Weiss (UMDNJ) and Margaret L. Knight (NJDHSS).

#### *Prepared by:*

William Bullock, <u>bbullock20@aol.com</u> Roger P. Bock Patience Akinosho

#### On behalf of:

Hoboken Family Planning, Hoboken, NJ The City of Plainfield Health Department, Plainfield, NJ



#### *Under the guidance of:*

Stanley H. Weiss, MD, University of Medicine and Dentistry of New Jersey-New Jersey Medical School (UMDNJ-NJMS) and School of Public Health (UMDNJ-SPH) (Principal Investigator)

Marcia M. Sass, BSRN, MSN, ScD, UMDNJ-SPH

Susan L. Collini, MPH, UMDNJ-NJMS

Daniel M. Rosenblum, PhD, UMDNJ-NJMS

Judith B. Klotz, DrPH, UMDNJ-SPH







## With the assistance of:

- The UMDNJ Clinical Research Group David L. Hom, MS, Loretta L. Morales, MPH, Benita Negron
- The Battelle Centers for Public Health Research and Evaluation Joanne P. Abed, PhD, Jennifer Brustrom, PhD
- The New Jersey Department of Health and Senior Services: the New Jersey Cancer Education and Early Detection Program, the New Jersey State Cancer Registry, and the Center for Health Statistics.

## Reviewed and edited by:

Jung Y. Kim, MPH, UMDNJ-NJMS
Daniel M. Rosenblum, PhD, UMDNJ-NJMS
Stanley H. Weiss, MD, UMDNJ-NJMS and UMDNJ-SPH

# **Table of Contents**

# Page

Introduction	6
Section 1 – County Demographic Profile	
Section 2 – Overview of Overarching Issues	
Resources	
Providers and Treatment	10
Community-based Screening Programs	11
Need to Expand Community-based Cancer Screening	
Population in Need of Smoking Cessation Programs	
Lack of Access to Oncology Services	
Lack of Cancer Treatment Funds	14
Need for a Countywide Cancer Coalition	
Section 3 – Cancer Burden	
Cancer Burden by Site	16
Breast Cancer	
Cervical Cancer	17
Colorectal Cancer	
Lung Cancer	19
Melanoma	20
Oral/Oropharyngeal Cancer	
Prostate Cancer	22
Other Cancer Sites/Issues	22
Bladder Cancer.	22
Section 4 – Discussion, Analysis and Recommendations	23
Recommendations for Local Priorities	
Recommendations for State Priorities	27
Closing Remarks	28
Deferences	20

# **Union County Cancer Capacity and Needs Assessment Report Summary**

#### Introduction

The Office of Cancer Control and Prevention (OCCP) of the New Jersey Department of Health and Senior Services (NJDHSS), in conjunction with the mandate from the Governor's Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey (Task Force), is developing comprehensive capacity and needs assessment reports concerning cancer, individualized for each county in the state. This Report Summary highlights key findings in the Union County report.

The Task Force released New Jersey's Comprehensive Cancer Control Plan (NJ-CCCP) in 2002. Each county was commissioned to develop a comprehensive capacity and needs assessment report, as part of the initial implementation steps for the NJ-CCCP. The full Report and this Report Summary were developed under the direction of University of Medicine and Dentistry of New Jersey (UMDNJ) and the Evaluation Committee of the Task Force, in furtherance of the NJ-CCCP (which can be found at:

http://www.state.nj.us/health/ccp/ccc\_plan.htm
Description: This particular assessment was funded by the OCCP through the following New Jersey Cancer Education and Early Detection (NJCEED) county agencies: Hoboken Family Planning and the City of Plainfield Health Department.

The purpose of the capacity and needs assessment reports is to identify the major cancer issues affecting each county and the county's available resources, or lack thereof, for cancer prevention, screening, and treatment, and to propose recommendations for improvement. The Union County Cancer Capacity and Needs Assessment (C/NA) Report<sup>2</sup> analyzes the population demographics and the cancer incidence and mortality rates and distribution of stage at diagnosis for the seven priority cancers of the NJ-CCCP (breast, cervical, colorectal, lung, oral, melanoma, and prostate), as well as the current resources available, in the county. These data guided the development of evidence-based recommendations and interventions to address cancer control priorities at local and state levels.

# **Section 1 – County Demographic Profile**

In 2000, Union County's population was determined to be 522,541 people residing in a land area of 103.3 square miles. Of New Jersey's 21 counties, Union County ranks 6<sup>th</sup> in population, 20<sup>th</sup> in size, and claims 6.2% of the state's population.<sup>a</sup> Also according to the 2000 Census, New Jersey, with 1,134 people per square mile, is the most densely populated state in the United States. Union County's population density in 2000 was 5,059 residents per square mile, making it the third most densely populated county in the country's most densely populated state.<sup>3</sup>

<sup>&</sup>lt;sup>a</sup> In general, percentages in this report are rounded to two digits.

In the 10-year period from 1990 to 2000, Union County experienced a population growth of 5.8%, less than the state's growth of 8.6% during this period. Although the county's white residents were in the majority in 2000, constituting 66% of the total, from 1990 to 2000, this portion of the population declined by 8.9%. The black population increased by 6.8% in this 10-year period and the Hispanic population exploded by 46%. As of 2000, larger proportions of the county population were black (21%) and Hispanic (20%) than was the case for the state population. The New Jersey population in 2000 was 14% black and 13% Hispanic.<sup>3,4</sup>

In 2000, the majority of the county population (56%) was concentrated in five of its 21 municipalities, Elizabeth City (23%), Union Township (10%), Plainfield (9.2%), Linden (7.5%), and Westfield (5.7%). Of these, Elizabeth and Plainfield are major inner-city communities, with large minority populations. Although very distant from each other, with Elizabeth bordering Essex County and Plainfield bordering Middlesex and Somerset counties, these two municipalities combined account for 32% of Union County's total population, 49% of its black, and 70% of its Hispanic residents.<sup>3</sup>

The median household income in Union County was \$55,339 in 1999, comparable to the corresponding state figure (\$55,146).° The per capita income was \$26,992 in Union County. The 2000 Census counted 43,319 Union County residents with income below the federal poverty level. The percentage of county residents with income below the federal poverty level was 8.4%, essentially the same as the state percentage (8.5%). The population below the poverty level included 11,682 white non-Hispanics (4.2% of the county's white non-Hispanic population); 13,772 blacks (13% of the county's black population); and 16,131 Hispanics (16% of the county's Hispanic population). The poverty figures reported for Elizabeth (18%) and Plainfield (16%) far exceed both the state and the county poverty rates. The majority of persons living below the poverty level in Elizabeth and Plainfield are Hispanics and blacks.<sup>5</sup>

Of note is the fact that the county poverty rate is driven by low per capita incomes for its black residents and Hispanic residents. The per capita income was \$18,586 for blacks and \$15,231 for Hispanics, compared to \$34,553 for white non-Hispanics. Adding to this picture is the fact that Elizabeth City is home to 36% of the county's elderly population who are living below the poverty level, and Plainfield contributes another 9.2% of this population. These two municipalities combined account for 45% of the county's poor elderly residents.<sup>3,5</sup>

In 2000, slightly more than one-fifth (21%) of the county's population aged 25 years and over had less than a high school education, compared to 18% for the state.

Persons aged 50 years and older constituted 29% of the county and state populations in 2000. Persons aged 65 and over represented 13.8% of the county population, compared to 13.2% for the state.<sup>3</sup>

A population's birth rate is often used as a measure of health. Hispanics had the county's highest birth rate in 2000 at 21.6 per 1,000 compared to 17.0 for Asian & Pacific Islander non-Hispanics, 16.3 for black non-Hispanics, and 11.1 for white non-Hispanics. In 2000, the county's black

<sup>&</sup>lt;sup>b</sup> Hispanics and non-Hispanics may be of any race. Racial categories include both Hispanics and non-Hispanics.

<sup>&</sup>lt;sup>c</sup> All figures for poverty and income are from the 2000 Census, but refer to the year 1999.

population had an age-adjusted death rate from all causes (1,044.4 per 100,000) that was 35% higher than that of the county's white population (773.7 per 100,000).<sup>6</sup> The county's black population also had higher age-adjusted death rates in 2000 – attributable to cancer, heart disease, stroke, and diabetes – than did their white counterparts. Also, the age-specific death rates for blacks were more than double the rates for whites in the 25- to 44-year age group (363.6 vs. 117.2 per 100,000 for black and white, respectively) and the 45- to 64-year age group (1,015.5 vs. 471.5).<sup>6</sup>

It is estimated that 21.7% of New Jersey adult males (aged 18 years and above) and 20.9% of New Jersey adult females were smokers in 2001, and 12.6% of the adolescent population (aged 12–17 years) were smokers in 1999–2000.<sup>7</sup> Since county-level data on smoking rates are not currently available, it is estimated that these percentages would be similar to those in Union County. The adverse impact of smoking on personal health is widely known including lung and bronchus and oral cavity and pharynx cancer deaths. Research indicates that by eliminating smoking, deaths due to these and other conditions not indicated here would each decrease by over 70%.<sup>7</sup>

### **Section 2 – Overview of Overarching Issues**

The City of Plainfield's Health Officer, who is also the county's NJCEED Program Director and Outreach Coordinator, provided the following overview concerning access to and resources for all services that address cancer in Union County.

While there are many dedicated services and facilities for cancer treatment located throughout Union County, cancer services appear to be fragmented and the county lacks a comprehensive plan to address cancer in the community.

It is also fair to say that, at present, there is no central control or process at the county level that could produce a comprehensive, countywide cancer control plan. However, this situation may change due to two important initiatives currently underway in the county: the Union County Cancer Capacity and Needs Assessment (C/NA) and the new public health standards being implemented in New Jersey. The Union County C/NA in and of itself is a community-based assessment of the county's health status with respect to cancer, and the implementation of the new public health standards will require Union County to conduct other community-based needs assessments to determine the overall health status of the county. Therefore, it is hoped that these two projects will lead to a comprehensive cancer prevention plan for Union County, provided the municipalities will be financially able to hire new, qualified employees to implement this plan.

According to the New Jersey Primary Care Association (NJPCA), in 2000 a combined total of 22.4% of the county residents was either uninsured (14.2%) or underinsured (8.2% covered by Medicaid). Moreover, the county's uninsured rate of 14.2% was a full percentage point higher than that of the state (13.2%). One percent (1%) of the county's total 2000 population (522,541) represents 5,225 people. Thus, according to these data from the New Jersey Primary Care Association, a large portion of the county's population (22.4%), slightly more than one out of

five of its residents, is under- or uninsured, and the county's percentage of people in this category is larger than the corresponding state percentage (20.8%).

This high percentage is confirmed by information from the National Cancer Institute's (NCI's) Atlantic Region Cancer Information Service (CIS). In June 2003, the NCI's CIS compiled Consumer Health Profiles maps and data for Union County, identifying clusters of the county population that are medically underserved. According to these data, 144,318 county residents (27.6% of the county's population of 522,541) are medically underserved. Thus, slightly more than one out of four county residents is medically underserved.

In less affluent communities, such as Elizabeth, Plainfield, Roselle, and Rahway, where 74% of the county's total population with income below the federal poverty level reside, this percentage may be much higher. Included in this population were 55% of the county's senior citizens aged 65 and above with income below the federal poverty level. These communities represented only 41% of the county's total population in the 2000 Census.<sup>5</sup> Therefore, a disproportionate share of the county's medically underserved population lives in these four communities.

According to key informants, many adults in the county's medically underserved population do not seek care, especially preventive care including cancer screening, mainly because they cannot afford it. Key informant comments included:

- These individuals are generally more concerned with basic survival, "putting food on the table," than they are with taking care of their own health.
- The illegal aliens (hereafter referred to as "undocumented") living in the county have the additional fear of being compromised (deported) if they seek care.
- Cancer prevention and screening are NOT currently high-priority items in the county.
- In general, males need more education about cancer prevention and early cancer detection than females. Therefore, all county male residents aged 40 and over should be a focus for early intervention and screening programs, because they have much higher cancer incidence and mortality rates than women, and they are less likely to seek preventive screening services.
- Black female residents of Union County should also be a focus, due to higher percentages of breast and cervical cancer diagnosed at the late stages of disease, which will be discussed further in Section 3.

Clearly, much work must be done in Union County to increase access to quality cancer services, to improve cancer screening rates, and to detect all cancers at the earliest possible stages. In this

<sup>&</sup>lt;sup>d</sup> According to the National Cancer Institute, the term medically underserved refers to individuals who lack access to primary care either because they are socioeconomically disadvantaged and may or may not live in areas with high poverty rates or because they reside in rural areas. The term also refers to individuals that reside in geographic areas where the Index of Medical Underservice (IMU) is 62 or less. The IMU is a weighted score derived from four variables: the ratio of primary medical care physicians per 1,000 population, infant mortality rate, percentage of population below the federal poverty level, and the percentage of the population aged 65 years and older. The data categorize the U.S. population into 62 groups based upon characteristics such as geography, demographics, lifestyle, and socioeconomic status. Within these 62 groups, 30 are classified as medically underserved.

regard, the Union County Cancer Capacity and Needs Assessment is an important step toward achieving these goals.

#### Resources

Detailed information regarding cancer screening, education, advocacy, treatment, palliation, and other activities has been collected to identify resources currently available in Union County. This information was included in the statewide Cancer Resource Database of New Jersey (CRDNJ).<sup>10</sup>

#### **Providers and Treatment**

There are five hospitals located in Union County: Muhlenberg Regional Medical Center in Plainfield; Overlook Hospital in Summit; Robert Wood Johnson University Hospital at Rahway; Trinitas Hospital in Elizabeth; and Union Hospital in Union.

These hospitals, along with many private physicians and several mammography facilities, offer access to significant site-specific cancer screening, diagnostic, and treatment resources for county residents. Based on the detailed information presented in the C/NA, the county seems to have an adequate supply of site-specific, state-of-the-art cancer services to serve its residents' needs. In addition, for those who can afford it, renowned cancer services are available nearby in New Brunswick, Hackensack, New York City, and even Philadelphia. Located closest to Union County are the Cancer Institute of New Jersey and Robert Wood Johnson University Hospital, both in New Brunswick. Based on information from key informants, many northern New Jersey residents with good health insurance seek cancer treatment in New York City.

Therefore, it is concluded that Union County is not lacking in the availability of site-specific cancer services. The problem is lack of access to these services for the medically underserved, the uninsured, underinsured, and undocumented individuals living in the county. But according to the Union County NJCEED outreach coordinator in Plainfield, obtaining referrals for cancer treatment in Union County is not difficult. For example, the Union County NJCEED coordinator reported that staff members at the Chandler Clinic, the Urology Department at Robert Wood Johnson, and the Cancer Institute of New Jersey are "wonderful" when it comes to accepting and treating patients referred to them by the NJCEED Program in Plainfield.

The Eric B. Chandler Health Center in New Brunswick (Middlesex County) accepts Plainfield's breast cancer screening patient referrals; the Urology Department at Robert Wood Johnson University Hospital (New Brunswick) accepts Plainfield's prostate cancer screening patient referrals; the Cancer Institute of New Jersey accepts Plainfield's cervical cancer screening patient referrals; and Muhlenberg Hospital's colorectal clinic accepts Plainfield's colorectal cancer screening patients. Of these four referral sites, only Muhlenberg Hospital is located in the county.

#### Community-based Screening Programs

The Union County's NJCEED Program provides free breast, cervical, colorectal, and prostate cancer screening services in Elizabeth and Plainfield in accordance with NJCEED guidelines. The eligible population is county residents aged 40 to 64, with no or little health insurance and with income less than 250% of the federal poverty level. The program's grantee, the City of Plainfield Health Department, has decided not to continue in this capacity after June 30, 2004. Hoboken Family Planning, one of the Hudson County NJCEED grantees, is serving as the interim grantee until a new one is established. In addition, the Union County NJCEED Program does not have a fully formed Cancer Coalition at this time. One will need to be developed once the new grantee is in place.

Plainfield Health Center is the only Federally Qualified Health Center (FQHC) located in Union County. Early detection and treatment of cancer is one of the FQHC's healthcare priorities. The City of Elizabeth is the home of the Elizabethport Community Health Center, a publicly funded primary care organization in the process of becoming a fully licensed FQHC. In addition, Overlook Hospital in Summit reports that the Community Health Center at Vauxhall provides oncology services for patients who have little or no insurance. Planned Parenthood of Greater Northern New Jersey (PPGN), serving Elizabeth and other parts of northern New Jersey, performs a substantial amount of breast and cervical cancer screening and some colorectal and prostate cancer screening in Union County.

There are 21 municipalities in Union County, 9 municipal health officers, and no regional health commission. At present, only one Union County municipal health department located in the City of Plainfield is providing cancer screening services. The other municipal health departments have apparently limited their cancer services to providing education.

Many community action and advocacy groups exist in the county that are attempting to provide the community and various populations of focus with cancer intervention assistance. An example of this is Overlook Hospital's Healthy Avenues Van. It has screened thousands of people since it first hit the road in 1996, including 8,000 in 2000 alone. In response to feedback and requests from the community, the van's mission was expanded to include educational programs on breast, colorectal, and prostate cancer. The other four county hospitals also have community outreach programs that no doubt are achieving some success in motivating county residents to seek age-and risk-appropriate cancer screening.

Yet support groups trying to modify behaviors of the populations of focus in Union County – such as the black community, Hispanic community, and the growing Asian Indian community – require leadership from those communities in cooperation with providers. For example, the City of Plainfield's Health Department reports having some recent success in reaching Hispanic men and black men for prostate and colorectal cancer screening, and Hispanic women and black women for breast cancer screening through such local community partnerships or through direct outreach efforts.

The American Cancer Society (ACS) has designated Hudson, Union, and Essex counties as its New Jersey Metro Region. According to the Regional Patient and Family Services Director for this region, his office is currently referring 10 to 15 patients per month to various NJCEED

clinics in the three-county area. The ACS maintains a useful web site and national call center<sup>e</sup> (1-800-ACS-2345 ext. 1) for patients and service providers. In addition, the ACS has numerous programs currently serving the county including: Reach to Recovery, a support program to help patients cope with breast cancer; Look Good... Feel Better, a program that teaches women undergoing treatment learn how to manage skin changes and hair loss; I Can Cope, an educational program providing information and encouragement for patients, families, and caregivers; and Road to Recovery, a volunteer program that provides transportation for cancer patients to and from treatment.

Union County is home to many large employers including Port Elizabeth, the largest container cargo port on the East Coast. It is likely that large employers, including the five hospitals in Union County, offer occupational health programs that address cancer, smoking cessation, and cancer early detection and screening. In general, smaller employers do not offer on-site health services and do not offer cancer screening services.

Faith-based organizations offer cancer education and screening referrals. For example, according to a key informant, St. John's Baptist in Scotch Plains offers free breast, cervical, colorectal, and prostate cancer screening once per year.

#### **Need to Expand Community-based Cancer Screening**

The NJCEED Program in Union County offers free breast, cervical, colorectal, and prostate cancer screenings to eligible county residents, as described earlier. However, due to funding limitations, breast and cervical cancer screening can be provided to only 18% of the eligible population. Thus, approximately 82% of the eligible population cannot be screened in the NJCEED Program. Some of these individuals are likely screened in other public and private healthcare settings. However, evidence suggests that those without health insurance frequently go without cancer screening tests, delaying diagnosis and leading to premature death. According to the Institute of Medicine, cancers occurring among the county's medically underserved population, especially the uninsured, are generally not being diagnosed at the earliest possible stages, and many of the individuals with cancer in this population do not receive treatment when it would be most effective.

\_

<sup>&</sup>lt;sup>e</sup> The national call center takes 1.2 million calls per year. See <a href="http://www.cancer.org/docroot/ESN/content/ESN\_3\_1X\_ACS\_National\_Cancer\_Information\_Center.asp?sitearea=ESN">http://www.cancer.org/docroot/ESN/content/ESN\_3\_1X\_ACS\_National\_Cancer\_Information\_Center.asp?sitearea=ESN (accessed 9/22/2004).</a>

According to the National Academy of Sciences' Institute of Medicine, individuals who lack access to oncology services because they are uninsured have a higher risk of dying from cancer. This study reached the following conclusions about the uninsured: 1) Quality and length of life are distinctly different for insured and uninsured populations. Uninsured adults are less likely than insured adults to receive recommended health screenings [e.g., mammograms, clinical breast exams, Papanicolaou (Pap) tests, colorectal screenings]; 2) People without health insurance go without cancer screening tests, delaying diagnosis and leading to premature death; and 3) When cancer is found, it is relatively advanced and more often fatal than in persons with health insurance coverage (e.g., uninsured women have a 30%–50% higher risk of dying than women with private insurance, and uninsured people with colon cancer face a 50% higher risk of death).

The Union County Consumer Health Profiles identified the following populations in the county as in need of cancer screening:<sup>9</sup>

Type of Screening	Gender and Age	<b>Estimated Number</b>
Prostate Cancer Screening	Males 50 and over	11,919
Colorectal Cancer Screening	Males 50 and over	10,210
Colorectal Cancer Screening	Females 50 and over	13,128
Breast and Cervical Cancer Screening	Females 40 and over	27,220

According to these data, approximately 12,000 county men aged 50 and over and 27,000 county women aged 40 and over – or 39,000 total county residents – live in clusters in need of age-appropriate cancer screening. A major expansion of the current community-based cancer screening facilities and additional financial resources would be required to screen these individuals. To accomplish this goal, it is essential that all community-based health organizations (not just the existing NJCEED clinics), especially the FQHC, community health centers, family planning clinics, municipal health clinics, hospital clinics, and private physicians located in the county, participate as screening sites and resources.

#### **Population in Need of Smoking Cessation Programs**

According to the New Jersey Department of Health and Human Services, one-sixth of all deaths among New Jersey residents are attributable to smoking, and it is estimated that one-fifth of New Jersey adults currently smoke, despite the fact that smoking is the most preventable cause of premature death. <sup>13,14</sup>

It is estimated that there are a total of 88,682 adult and adolescent smokers in Union County.<sup>2</sup> In addition, data from the NCI's CIS identified 49,437 county males and 52,862 county females aged 18 and over at risk of smoking because they live within medically underserved clusters.<sup>9</sup> Therefore, at least 103,000 of the county's 392,600 residents aged 18 and over (26% of the county's adult population) are in need smoking prevention education and smoking cessation programs. According to a key informant, the only method found effective in helping people quit smoking is nicotine replacement therapy (NRT). New Jersey offers publicly funded NRT at its QuitCenters. Yet Union County's QuitCenter at Trinitas Hospital closed recently due to lack of funds. With funding cuts of two-thirds to the statewide QuitCenter Program, it is not likely that a Union County based QuitCenter will be funded again in the near future.

#### **Lack of Access to Oncology Services**

The principal cancer problem facing Union County is the lack of access to oncology services for the uninsured, underinsured, and undocumented. The underinsured can include Medicaid-eligible individuals, if they are having difficultly locating oncology services. The underinsured can also include seniors covered by regular Medicare because Medicare does not currently pay for prescription drugs, including cancer medications. The uninsured, underinsured, and undocumented individuals living in the county constitute the medically underserved population.

According to the NCI's CIS's estimate, 144,318 county residents (27.6% of the county population) are medically underserved. Informants interviewed as part of this project agreed with this assessment.

The medically underserved either lack access to oncology services or experience major difficulty identifying these services in the event they are required. The undocumented among this population with no proof of residency have little or no access to these services, except for hospital emergency services.

#### **Lack of Cancer Treatment Funds**

Informants in the region cited instances involving charity care cancer patients where very expensive hospital inpatient and intensive care unit (ICU) services had to be utilized, including ventilators and morphine drips, because patients could not afford to buy the pain medicine and antibiotics they required and charity care does not cover these medications for outpatients. Chemotherapy is another example cited by regional informants where expensive inpatient hospital services are used to provide cancer treatment when much cheaper outpatient services should be utilized. In some instances, the only way to secure payment for chemotherapy is to admit the patient to a hospital because the payor (e.g., charity care) does not cover this treatment on an outpatient basis. Because this treatment can be provided in an outpatient setting, patients with insurance coverage receive chemotherapy in doctors' offices, whereas patients without insurance coverage are sent to the hospital for treatment. As with medications, significantly higher hospital expenses can be avoided by funding chemotherapy on an outpatient basis. Given the substantial risks of hospital-acquired infection, this suggests the potential for increased morbidity and mortality as well.

The county's five hospitals are providing a substantial amount of uncompensated cancer care each year. Residents in all Union County communities have become aware that hospital emergency rooms cannot turn away patients. Uninsured, underinsured, and undocumented individuals with cancer and other major health problems come to the Union County hospital emergency rooms knowing that the county hospitals must treat them.

Although the specific amount of uncompensated care is not known, it can be estimated. According to the New Jersey Hospital Association, in 2002, charity care billings for the five county hospitals to cover uncompensated care were approximately \$50 million *at Medicaid rates*. In 2004, the county hospitals received reimbursement at 60% of these Medicaid rates (approximately \$30 million). Three of these hospitals – Union, Rahway, and Overlook – were reimbursed only 12%. Therefore, according to the New Jersey Hospital Association, the five Union County hospitals are absorbing an estimated \$20 million per year in uncompensated charity care costs.

Undoubtedly, cancer care represents a material portion of these high annual amounts of charity care costs. The county has a large percentage of medically underserved individuals, likely resulting in higher rates of late-stage cancer and cancer mortality, <sup>12</sup> and many individuals among this high-risk population access the healthcare delivery system for cancer care through the most expensive route, hospital emergency services. A rough and possibly conservative estimate of the

annual amount of uncompensated cancer care costs that Union County hospitals are absorbing would be \$4 million per year. This estimate does not include cancer care provided by Union County doctors. One area doctor estimated this cost at \$200,000 to \$300,000 per year in lost revenues for every oncologist who accepts Medicaid, treats uninsured, and accepts hardship cases. Taking all these factors into account, it is estimated that the amount of uncompensated hospital and physician cancer care in Union County is approximately \$6 million per year.

#### **Need for a Countywide Cancer Coalition**

A countywide cancer coalition would be a good place to begin addressing the cancer screening and smoking cessation needs in Union County. A countywide cancer coalition would facilitate dissemination of information about services and providers, as well as provide a forum for professionals, patients, and survivors to discuss key issues. In addition, local health officers and community leaders and advocates should be encouraged to become more involved in cancer control planning. Especially crucial in Union County is the need to identify local leadership of at-risk/underserved communities and engage them in this process.

A Union County Cancer Coalition needs to be a proactive body that advocates for early detection, screening, and treatment for all county residents through partnerships with state and local governments, the healthcare industry, the business community, unions and other membership organizations, the media, the education community, faith-based organizations, community action groups, and the general public. In Section 4 of this report, specific recommendations will be presented regarding ways to address the issues of coalition-building, outreach, education, screening, and treatment in Union County. The recommendations include establishing a countywide cancer prevention strike force (coalition); conducting a comprehensive, culturally sensitive outreach program; organizing a network of physicians and ambulatory health clinics; and expanding the county's screening program to reach the county's at-risk population.

#### Section 3 – Cancer Burden

All incidence<sup>15</sup> and mortality<sup>16</sup> rates cited herein are per 100,000 and age-adjusted to the 2000 U.S. population standard<sup>3</sup>. All county and state rates are average annual rates during 1996–2000. For simplicity, the 1996–2000 average annual age-adjusted incidence or mortality rate hereinafter will be abbreviated and referred to as incidence or mortality rate, respectively. The reason the five-year average has been routinely used is that the small number of cases in a single year leads to statistical variations that are not generally meaningful. For U.S. incidence rates, 1999 or 2000 rates were used. Unless otherwise specified, all rates are for invasive cancer only.

The following table presents the county's incidence and mortality rates, along with the estimated prevalence, for all cancer sites combined and for each of the seven NJ-CCCP priority cancers.

	Estimated Prevalence <sup>d</sup>	Incidence per 100,000 <sup>e</sup>	Mortality per 100,000 <sup>e</sup>	
All Cancers, Union County				
Male	8,356	649.4	254.7	
Female	12,559	455.9	178.8	
NJ-CCCP Priority Cancer by Gender				
Breast, female	4,906	142.5	33.1	
Cervical, female	499	10.2	3.0	
Colorectal, male	933	75.8	28.4	
Colorectal, female	1,387	53.4	19.7	
Lung, male	291	89.0	67.1	
Lung, female	342	48.6	36.6	
Melanoma, male	489	20.4	3.8	
Melanoma, female	624	12.6	1.5	
Oral/Oropharyngeal, male	221	14.3	4.7	
Oral/Oropharyngeal, female	163	6.1	1.8	
Prostate, male	3,672	215.7	37.8	

<sup>&</sup>lt;sup>a</sup> Based upon the NJ-CCCP.

#### **Cancer Burden by Site**

#### **Breast Cancer**

In Union County, an estimated 4,906 women were living with diagnosed breast cancer at any point in time during the period 1996–2000. The county breast cancer incidence rate (142.5 per 100,000) was slightly higher than the rates in New Jersey (138.5) and the U.S. (134.0) for women of all races. White women in Union County (148.6 per 100,000) had a 4% higher incidence rate of breast cancer compared to white women in the state (143.4) and 9% higher than in the U.S. (136.3). The incidence of breast cancer increases with age. For example, in Union County, the breast cancer incidence rate for women aged 40 to 49 years (167.0 per 100,000) was 7.4 times higher than the rate for women aged 15 to 39 years (22.5); the incidence rate for those aged 75 years and over (485.6) was nearly three times that for women aged 40 to 49 years.

<sup>&</sup>lt;sup>b</sup> Age-adjusted to 2000 U.S. Census population standards. Age-adjustment is used to describe rates in which statistical procedures have been applied to remove the effect of differences in composition (specifically, variations in age distribution) of the various populations. This is important in order to portray an accurate picture of the burden of cancer, since cancer is known to disproportionately affect persons of differing ages.

<sup>&</sup>lt;sup>c</sup> Rates are average annual rates during the time period 1996 through 2000.

<sup>&</sup>lt;sup>d</sup> Prevalence is the measurement of burden of disease in the population at a particular point in time. Within this report, it represents the number of people alive who have ever been diagnosed with the disease. Prevalence figures given here are rough theoretical estimates, based on a number of assumptions, and computed by applying national prevalence-to-incidence ratios to Union County's average annual crude incidence counts for the five years 1996–2000, separately for each gender. Actual prevalence is likely to be of the same order of magnitude as the estimate.<sup>17</sup> <sup>e</sup> Incidence and mortality are gender-specific, age-adjusted annual rates, not counts. A rate at least 10% higher than the corresponding state rate is shown in bold italics.

f "All cancers" represents the sum of all invasive cancer during the time period, not just the seven cancers presented in detail below.

Union County's breast cancer mortality rate (33.1 per 100,000) was slightly higher (6%) than both the New Jersey (31.3) and the U.S. (27.7) rates. The incidence of breast cancer is generally higher for white women than black women. Yet, the breast cancer mortality rate for black women remains higher than that for white women. The Union County breast cancer mortality rate for black women (42.5 per 100,000) was 37% higher than the rate for white women in the county (31.0) and 14% higher than the rate for black women in the state (37.2). Further, while 20% of all breast cancer deaths in the county occurred among black women, the corresponding figure for the state was only 13%. The mortality rates for Hispanic women in Union County and in New Jersey were 13.4 and 16.0 per 100,000, respectively.

A substantial percentage of breast cancers diagnosed in black women and Hispanic women in Union County were not detected at the early stages. For example, 38% of cases occurring among black women in the county were diagnosed in the late (regional or distant) stages, compared to 27% of cases among white women in the county. Among Hispanic women in the county, 37% of cases were diagnosed in the late stages.

Based on the above data, there are three populations of focus in Union County for outreach, education, early detection, and treatment of breast cancer: black women due to higher mortality and the higher percentage of late-stage diagnoses; Hispanic women due to the higher percentage of late-stage diagnoses of breast cancer; and women of all races and ethnicities aged 40 and over because the incidence of breast cancer increases with age.

#### Cervical Cancer

A total of 147 new cases of invasive cervical cancer were reported in Union County from 1996 through 2000, resulting in a five-year average annual incidence rate of 10.2 per 100,000, which was slightly lower than the state rate (10.9 per 100,000). Although blacks constitute only 21% of the county's total population, black women represented 32% of the cervical cancer cases in the county. In contrast, black women in New Jersey represented 21% of cervical cancer cases in the state. The Hispanic population (20% of Union County's population) comprised 22% of the cervical cancer cases in the county, compared to 14% of cases in the state. The average annual cervical cancer incidence rate for black women for the period 1996–2000 was 17.6 per 100,000, which was similar to the rate among black women statewide (17.9 per 100,000) but double the rate among women in the county (8.8). The cervical cancer incidence rate among Hispanic women (16.2 per 100,000) was also high in the county, although similar to that in the state (15.8). The cervical cancer incidence rate among women in the county aged 50 to 64 years was 17.5 per 100,000 and rose to 21.8 per 100,000 among those 75 years and over.

Cervical cancer is a preventable disease. Yet, an average of 9 deaths due to cervical cancer occurred in Union County per year from 1996 through 2000, accounting for 6.3% of cervical cancer deaths statewide. During this same period, the average annual death rate in Union County for cervical cancer (3.0 per 100,000) was similar to the corresponding rates in the state (3.1) and in the nation (3.0). The cervical cancer mortality rate for black women in the county (7.0 per

\_

<sup>&</sup>lt;sup>g</sup> Hispanics and non-Hispanics may be of any race. Racial categories include both Hispanics and non-Hispanics. Data on non-Hispanics are not available.

100,000) was far higher than that for white women (2.3), consistent with the mortality rate for black women in New Jersey (6.5), and higher than the mortality rate for black women in the U.S. (5.9). Of the cases of cervical cancer in Union County for which the stage at diagnosis was available, 53% of cases (21 out of 40) among black women were diagnosed at the regional stage, compared to 32% of cases (27 out of 84) among white women. Within Union County and the state overall, the percentage of cervical cancer diagnosis at the localized stage was highest among the younger age groups (15–39 years and 40–49 years), and the percentage of cases diagnosed at the regional/distant stage increased among women aged 50 and over.

An estimated 499 women were living with diagnosed cervical cancer in Union County at any point in time during the period 1996–2000. The differences in cervical cancer incidence, mortality, and distribution of stage at diagnosis suggest disparities in access to healthcare exist. Based on the data above, black women and Hispanic women are at greatest risk. The majority of women in this high-risk population can be found in the municipalities of Elizabeth and Plainfield. These municipalities also have poverty levels that exceed the county and state levels.

#### Colorectal Cancer

An estimated 933 men and 1,387 women were living with diagnosed colorectal cancer in Union County at any point in time during 1996–2000. Union County's colorectal cancer incidence rate was higher in men than in women (75.8 versus 53.4 per 100,000, respectively). For the five-year period 1996–2000, the average annual age-adjusted colorectal cancer incidence rate for black men (87.4 per 100,000) was higher than both the rate for white men in the county (73.9) and the rate for black men statewide (77.1). The colorectal cancer incidence rate among Hispanic men was higher in the county (86.3)<sup>h</sup> than in the state overall (61.8).

Black women (61.7 per 100,000) reported a higher incidence rate of colorectal cancer than did white women in the county (52.9) as well as black women statewide (56.6).

Union County and New Jersey men and women showed an increase in the colorectal cancer incidence rate with age, with incidence increasing sharply at age 50 and over. In Union County, the colorectal cancer incidence rate per 100,000 was 23.1 for men aged 40–49 years, compared to 115.6 for those aged 50–64 years, 330.8 for those aged 65–74 years, and 529.5 for those aged 75 years and over. A similar pattern was observed for women in Union County.

For men of all races, the colorectal cancer death rate in the county (28.4 per 100,000) was similar to the corresponding state rate (29.5) and higher than the U.S. rate (25.8). The colorectal cancer mortality rate for white men in the county (26.5 per 100,000) was slightly lower than the corresponding state rate (29.4), but the mortality rate for black men in the county (38.7) was higher than that for black men statewide (35.9).

\_

<sup>&</sup>lt;sup>h</sup>During the period of 1996–2000, there was a substantially higher colorectal cancer incidence rate (152.4 per 100,000) among Hispanic males in the year 1996, a rate 80% higher than the next highest rate for a single year during this period, thus raising the average for the five-year period. The 1997–2001 average annual colorectal cancer incidence rate among Hispanic males in Union County was 76.7 per 100,000, 22% higher than the New Jersey rate (63.0) for the same time period, suggesting that the rate is persistently somewhat higher among Hispanic males in the county.

The death rate due to colorectal cancer among women in Union County (19.7 per 100,000) was similar to the New Jersey rate (20.1) and slightly higher than the U.S. rate (18.0). The county death rate for white women (19.2) was similar to that of the state (19.8), but higher than that of the U.S. (17.5). Black women had the highest death rate for colorectal cancer in the county (23.8) of groups for which separate statistics were available. The death rate among Hispanic women was low (12.7 per 100,000, a rate based on fewer than 20 deaths over the five-year period).

In Union County, 51% of colorectal cases among women and 51% of cases among men were diagnosed in the late stages. Hispanic women in the county were more likely to be diagnosed at the early stages (49%) than other women in the county.

As indicated earlier, 10,210 men and 13,128 women aged 50 and over have been identified as medically underserved regarding colorectal cancer screening. This medically underserved population is in need of free or low-cost screening services.

#### Lung Cancer

An estimated 194 men and 189 women were living with diagnosed lung cancer in Union County at any point in time during the period 1996–2000. From 1996 through 2000, 1,805 new cases of lung cancer in Union County were reported, 6% of all new cases of lung cancer in the state. The lung cancer incidence rate among all men in the state was 92.5 per 100,000, compared to 89.0 per 100,000 for the county. Women also had a lower incidence rate of lung cancer in the county (48.6 per 100,000) than in the state (55.4 per 100,000).

Differences in incidence and mortality rates of lung cancer exist among different racial groups. The incidence rate of lung cancer among black men in the county (104.1 per 100,000) was higher than the rate among white men (85.3), which is consistent with the statewide pattern (118.1 and 91.0 among black men and white men, respectively). The lung cancer mortality rate for black men (88.4 per 100,000) was much higher than that reported for white men (64.6), also consistent with the statewide disparity (99.9 and 73.7 among black men and white men, respectively). Among women, black women (39.0) had a lower incidence rate than did white women (50.4), which is consistent with the state (51.9 and 57.0 among black women and white women, respectively). However, black women (35.9) and white women (37.2) in the county had similar mortality rates, also consistent with the statewide pattern (41.8 and 42.5 among black women and white women, respectively).

Hispanic men in the county accounted for 11% of new lung cancer cases in the state and had an 18% higher incidence rate (79.4 per 100,000) than did Hispanic men in the state (67.2). Further, the lung cancer mortality rate among Hispanic men was 14% higher in the county (40.4) than in the state (35.5).

The incidence of lung cancer increases with age for both men and women, especially at age 50 and over. For men aged 40 to 49 years, the county (26.3 per 100,000) reported a slightly higher lung cancer incidence rate than did the state (24.0). For men in Union County aged 50 to 64

years, the lung cancer incidence rate increased to 151.9 per 100,000 and to 421.3 per 100,000 for men aged 65 to 74 years.

Women in Union County had a lower death rate from lung cancer (36.6 per 100,000) than did women in the state (41.6) and in the U.S. (40.7). White women accounted for 85% of the deaths due to lung cancer among all women in the county. The lung cancer mortality rate among Hispanic women in the county (10.4) was lower than in the state (10.9) and in the U.S. (15.1).

Tobacco smoking is responsible for nearly 90% of all lung cancer cases. It is estimated that 49,437 men and 52,862 women aged 18 and over in Union County who live in medically underserved clusters are at risk of smoking and would be the population of focus for smoking cessation or anti-smoking educational programs. 9

#### Melanoma

An estimated 489 men and 624 women were living with diagnosed melanoma in Union County at any point in time during the period 1996–2000. A total of 431 new cases of melanoma were reported in the county during this period. Not surprisingly, over 98% of melanoma cases among men in the county and the state were among white men. Among white men, similar percentages in both the county (2.9%) and state (3.5%) were diagnosed in the distant stage.

The melanoma incidence for men of all races in Union County for the five-year period was 20.4 per 100,000, compared to 20.1 for the state. The incidence rates of melanoma in Union County were 24.6 for white men and 10.6 for Hispanic men. The melanoma incidence rate for black men in the county was suppressed due to the small number of cases; even at the state level, the melanoma incidence rate for black men was less than 1.0 per 100,000.

The melanoma incidence rate in Union County for white women was 15.4 per 100,000, compared to 13.9 for white women in the state. Among women, county rates were lower than state rates for the age groups 15–39 and 50–64. However, among the 65–74 and 75+ age groups, the county rates were 26% and 14% higher than the state rates (42.5 and 33.7 for the 65–74 age group and 44.2 and 38.9 for the 75+ age group, in the county and the state, respectively).

Overall, the melanoma mortality rates in the state were higher than the national rates for both genders. For all men, the death rate from melanoma in Union County (3.8 per 100,000) was lower than both the New Jersey rate (4.4) and the U.S. rate (3.9). The melanoma mortality rate for white men in the county (4.5) was slightly lower than the rate for white men in New Jersey as a whole (4.9).

For the period 1996–2000, the melanoma death rate was 1.5 per 100,000 for all women in Union County, which was lower than the corresponding rates in the state (1.9) and in the nation (1.8). White women in the county had a lower death rate (1.9) than did white women in the state (2.2) and in the U.S. (2.0).

In general, the percentages of melanoma cases among women in the county diagnosed *in situ*/localized stage were lower than the percentages in the state for all age groups, except the

oldest age group (75+). However, the percentage of unstaged cases was also generally higher in the county than in the state. For example, among women aged 50–64 years, 78% of cases in the county were diagnosed at the early stages, compared to 86% in the state, but 13% of the cases among women in the county were unstaged compared to 8% in the state.

In conclusion, the populations of focus in Union County for outreach, education, early detection, and early treatment of melanoma are white men and women aged 50 and above.

#### Oral/Oropharyngeal Cancer

Oral and oropharyngeal cancer include cancer of the lip, tongue, floor of the mouth, palate, gingiva and alveolar mucosa, buccal mucosa, and oropharynx. A total of 221 men and 163 women were living with diagnosed oral/oropharyngeal cancer in Union County at any point in time during the period 1996–2000.

Nearly 6% (169) of oral/oropharyngeal cancer cases among men in New Jersey (2,960 cases) occurred in Union County. This translated to an incidence rate of 14.3 per 100,000 for men in the county, compared to 15.7 for men in the state. In Union County, men (14.3 per 100,000) were diagnosed with oral/oropharyngeal cancer more frequently than women (6.1 per 100,000).

Gender distribution of oral/oropharyngeal cancer in the county varied by race. Black men (20.7) had a higher oral/oropharyngeal cancer incidence rate than did white men (13.5), which was consistent with the corresponding state rates (22.8 and 14.9 among black men and white men, respectively). However, the reverse was true among women within the county. White women in the county (6.2) had a higher oral/oropharyngeal cancer incidence rate than did black women (5.2), while black women statewide (6.9) had a higher incidence rate than white women (6.3).

Compared to New Jersey, oral/oropharyngeal cancer incidence rates among men in Union County were slightly lower across all age groups, except in the 65- to 74-year age group, where the county incidence rate (59.9 per 100,000) was slightly higher than the New Jersey rate (57.1). The highest incidence rate of oral/oropharyngeal cancer among men was found in this age group (65–74 years) in both the county and the state. Women in Union County had a noticeably lower incidence rate than those in the state for the age group 50 to 64 years (9.9 versus 12.9 per 100,000, respectively). In Union County and New Jersey, women aged 15–39 years had the lowest incidence rates of oral/oropharyngeal cancer (2.2 and 1.1 per 100,000 in the county and the state, respectively), while the highest oral/oropharyngeal cancer incidence rate was noted among women aged 75 years and over (27.0 and 30.0 in the county and the state, respectively).

For all men, the death rate due to oral/oropharyngeal cancer was higher in the county (4.7 per 100,000) than in the state (4.2) and in the U.S. (4.4). The oral/oropharyngeal cancer mortality rate for black men in the county (10.2 per 100,000) was slightly higher than the rates for black men in New Jersey (9.6) and in the U.S. (7.9), and was more than double the rate for white men

-

<sup>&</sup>lt;sup>i</sup> The oral/oropharyngeal mortality rate for black men in the county was based on fewer than 20 deaths during the five-year period.

in the county (3.9). The oral/oropharyngeal cancer mortality rate among all women in the county (1.8 per 100,000) was similar to the corresponding state rate (1.6).

The distribution of oral/oropharyngeal cancer by stage at diagnosis was similar in the county and state for both men and women. However, a slightly higher percentage of cases among men were diagnosed in the late stages in the county (62%) than in the state (58%). While 74% of staged cases among black men in the county were diagnosed at the regional or distant stage, the corresponding percentage of cases among white men was much lower (59%), although this difference was not statistically significant.

#### Prostate Cancer

An estimated 3,672 men were living with diagnosed prostate cancer in Union County at any point in time during the period 1996–2000. The prostate cancer incidence rate for all men in Union County (215.7 per 1100,000) was higher than the corresponding rates in the state (194.3) and in the U.S. (162.0).

The prostate cancer incidence rate for black men in the county (307.2 per 100,000) was 53% higher than the rate for white men in the county (201.3); these county rates were slightly higher than the corresponding state rates (287.9 and 186.4 for black men and white men, respectively).

During the period 1996–2000, an average of 78 Union County men died from prostate cancer per year, of which 57 (74%) were white and 20 (26%) were black. Two percent of deaths due to prostate cancer occurred among Hispanic men. The prostate cancer death rate in Union County was 37.8 per 100,000, second highest among the 21 New Jersey counties and 15% higher than the corresponding state and U.S. rates (both 32.9). The county prostate cancer mortality rate for black men (84.0 per 100,000) was more than double that for white men (32.2).

In Union County, a higher percentage of cases among black men were diagnosed at the regional and distant stages of prostate cancer (16%) than of cases among white men (9.4%); this difference was statistically significant (p<0.001).

The distribution by stage at diagnosis of prostate cancer in the county was similar to that in the state. Those aged 75 and over in Union County and New Jersey were diagnosed at the *in situ* and localized stages slightly less frequently when compared to other age groups.

Based on the NCI's estimate, 11,919 men in the county aged 50 and over (18% of the county's total male population aged 50 and over) are in need of prostate cancer screening awareness.

#### Other Cancer Sites/Issues

**Bladder Cancer.** During the period 1996–2000, an average of 140 new cases of bladder cancer occurred per year in Union County (99 among men and 41 among women), representing 6.3% of new bladder cancer cases in the state.<sup>18</sup>

Bladder cancer incidence was 3.5 times higher among men (43.6 per 100,000) than women (12.3 per 100,000) in Union County. The incidence rate for the disease among white men in the county (47.2), although higher than that for black men (25.9), was similar to the state rate for white men (48.2). Thus, white men are twice as likely as black men to develop bladder cancer.

The bladder cancer incidence rate for all women in Union County was 12.3 per 100,000, similar to the rate among women statewide (11.8). Of the new cases of bladder cancer among women in Union County, white women accounted for 90% of those cases, and black women 10%.

Mortality due to bladder cancer was at least 3.5 times higher among men than women in the county, the state, and the U.S. During the period 1996–2000, there was an average of 24 deaths (17 among men, 7 among women) due to bladder cancer in Union County per year. The mortality rate for bladder cancer among men in Union County (8.0 per 100,000) was lower than that for the state (9.4). Union County contributed only 5% of state deaths from bladder cancer.

The bladder cancer mortality rates among white men and white women in the county (8.0 and 2.2 per 100,000, respectively) were lower than the corresponding state rates (9.7 and 2.7 among white men and white women, respectively) but similar to the corresponding U.S. rates (8.0 and 2.3, respectively). Mortality rates at the county level for black or Hispanic men and women were suppressed due to the small number of deaths, albeit the New Jersey rates for these subpopulations were higher than the corresponding U.S. rates.

Based on these data, the population of focus for bladder cancer should be white men.

# Section 4 – Discussion, Analysis and Recommendations

#### **Recommendations for Local Priorities**

Union County has a large medically underserved population, estimated to be as large as 144,318 of the county's 522,541 total residents, or 27.6% of its total population. In less affluent communities such as Elizabeth, Plainfield, Roselle, and Rahway, where 74% of the county's total population with income below the federal poverty level resides, the proportion of medically underserved is most likely much higher. As described in Section 3, incidence and mortality rates can be reduced and the percentage of early-stage diagnoses can be improved for many cancers in Union County. Therefore, the local priorities are:

**Local Priority 1 – Improve access for low-income and minority individuals.** (AC-1, AC-1.2.2, AC-2, AC-2.1.7, AC-4, AC-4.1.2, AC-4.1, AC-4.2 and AD-3)<sup>j</sup>

Local Priority 2 – Promote early detection and reduce cancer mortality. (AC-1, AC-1.2.4, AC-2, AC-2.5, AC-2.1, AC-4, AD-1, AD-2, AD-3)

-

<sup>&</sup>lt;sup>j</sup> In parentheses are references to relevant goals (e.g., AC-1), objectives (e.g., AC-1.1), or strategies (e.g., AC-1.1.1) outlined in the NJ-CCCP. AC refers to issues related to Access and Resources; AD refers to Advocacy.

**Strategies for addressing local priorities.** The strategies below are recommended to address the two priorities cited above.

- Design and implement a large-scale, culturally sensitive, outreach program to educate
  and motivate the county's medically underserved population, as well as all other county
  residents, to adopt healthier lifestyles and, when appropriate, to obtain appropriate cancer
  screening services.
- Marshal the resources needed to execute this new, expanded Union County Cancer
  Prevention Program, including the resources necessary to follow up on the increased
  volume of cancerous and precancerous conditions that will be reported as a result of this
  new program.

**Recommendations for addressing local priorities.** In the near term utilize the extension of the County Capacity and Needs Assessment through December of 2004 to build the foundation for this new Cancer Prevention Program in Union County. In the future, after December of 2004, secure grant funds from the State of New Jersey Cancer Control Program for this expanded outreach and screening program. Specifically:

- Recruit members for a first-rate, countywide, culturally sensitive, and proactive Cancer Coalition who are willing and able to creatively and effectively address the cancer problems in Union County and who will act as the cancer prevention strike force for the county.
- Appoint a Coalition Chairman, set up committees, develop a plan based on the Union County Capacity and Needs Assessment and other information, and design the outreach program.
- Organize a network of existing ambulatory clinics and private physicians into a coordinated cancer prevention network that will execute this expanded cancer screening program.
- Implement an outreach program and use it to increase the county's current screening rates for all county residents and most especially for those in the medically underserved population.
- Coordinate the care for those diagnosed with cancer or precancerous conditions.

*Network of clinics and private oncology doctors.* The network of clinics upon which the new Union County Cancer Prevention Program will be built includes, but is not limited to the Plainfield Health Department's NJCEED Program, the Plainfield Health Center, the Elizabethport Community Health Center, the Community Health Center at Vauxhall, the Colorectal Clinic at Muhlenberg Hospital, and the Elizabeth center of Planned Parenthood of Greater Northern New Jersey.

These six agencies operate many clinics in the county and have made significant, long-term, culturally sensitive investments to develop trust in their respective communities and the populations they serve. Three of these organizations receive grant funds from and operate under standards set forth by the Bureau of Primary Health Care of the U.S. Department of Health and

Human Services. These standards are designed to break down financial and cultural barriers that prevent the medically underserved from receiving diagnosis and treatment.

This capacity and needs assessment identified several key physicians who should participate in this network. These physicians, and all county physicians and clinics, should be encouraged to participate in the coalition and the provider network to help support a coordinated system of care to reduce the cancer burden of Union County residents.

**Projected costs of an expanded outreach and screening program.** The Hoboken Family Planning NJCEED Program in Hoboken, New Jersey, subcontracted cancer screening at the following unit costs:

- \$262 for a primary gynecology service visit, which included the cost of a comprehensive gynecological exam; breast, cervical, and colorectal cancer screening; sexually transmitted disease screening; and the related lab tests.
- \$110 for a male prostate and colorectal screening visit, which included the cost of the exam and the related prostate specific antigen (PSA) test and other lab tests.

New Jersey residents aged 40–64 years who are uninsured or underinsured and have incomes below 250% of the federal poverty level are eligible to receive breast (female), cervical, colorectal, and prostate cancer screening through the NJCEED Program. Current program funding limits screening to about 18% of this eligible population in need of breast and cervical cancer screening. This leaves a significant portion (approximately 82%) of the eligible population at risk of not receiving screening. In order to estimate the additional funding needed to cover or reduce this gap, it is necessary to know the number of persons eligible. Based upon the best information available, <sup>3,8,19</sup> we estimate that the at-risk population in Union County includes approximately 8,742 males and 9,439 females, or 18,181 persons total. Therefore, a large number of county residents are at risk of being diagnosed with late-stage cancer because they do not have health insurance. This calculation is based on several assumptions, <sup>m</sup> leading to a

<sup>1</sup> The county's population between the ages of 40 and 64 consisted of 76,150 males and 82,222 females, or 158,372

\_

screenings are offered.

reasonable. On the positive side, some county residents who meet the NJCEED eligibility requirements are being screened for cancer by their private doctors, the public health system, when hospitalized, or at health fairs where free

<sup>&</sup>lt;sup>k</sup> State NJCEED Program officials confirmed this estimate of 18% for breast and cervical cancer screening. There is no federal funding for colorectal and prostate cancer screening, so the total funding available for screening for these cancers is even less.

persons total.<sup>3</sup> In 2002, the county's uninsured rate was estimated to be 14%,<sup>8</sup> and the NJCEED Program's screening rate is about 18% of the eligible population. Multiplying the population aged 40–64 (76,150 males and 82,222 females) by the percent uninsured in the county (14%) provides a rough estimate of the population eligible for NJCEED. This estimate (10,661 males and 11,511 females) is multiplied by 82% to estimate the at-risk population, those eligible persons for whom NJCEED funding is not available (8,742 males and 9,439 females).

This calculation is based on the assumption that (1) the county's population aged 40 to 64 years has the same percent uninsured (14%) as the county's total population; and (2) the county's NJCEED screening percentage is the same as the state's percentage (18%). From 1999 to 2002, the statewide percentages of uninsured for all residents aged 35 to 65 years ranged from 10%–16%.<sup>19</sup> As stated earlier in this report, Union County had 8.4% of its total population living at less than 100% of the federal poverty level in 2000, essentially the same as the state's poverty rate (8.5%). However, the figures reported for Elizabeth (17.8%) and Plainfield (15.9%), two of Union County's largest urban areas, far exceed both the state and county rates. For these reasons, the 14% figure for the uninsured rate in Union County for those aged 40 to 64 with incomes less than 250% of the federal poverty level is considered

reduction in our estimate from 18,181 to 16,000 county residents aged 40 to 64 years who are at risk of not receiving cancer screening.

Based on this estimate of 16,000 persons at risk of not receiving screening, and the county's percentages of men (48%) and women (52%) aged 40 to 64 years, it is estimated that this at-risk population consists of 7,680 men and 8,320 women. Based on the unit costs above, screening would cost \$3.02 million (\$844,800 for men and \$2.18 million for women). Assuming that this type of screening effort could take place over a four-year period, the screening cost would be \$756,160 per year. Much of the outreach program could be administered through a community outreach organization such as Hopes, Inc. (located in Hoboken) for an expenditure of \$100,000 per year. Therefore, the total cost to screen 16,000 of the at-risk individuals in Union County is estimated to be about \$780,000 per year for four years, or \$3.12 million in total for the four-year period.

#### Funding the new Union County Cancer Prevention Program.

- a) Shift current state expenditures from hospital care to preventive care. Over the long term, investing money in this expanded cancer outreach, screening, and early detection program could avoid expensive healthcare costs such as emergency room services and inpatient services, especially ICU services, currently utilized to treat late-stage cancers. This could be accomplished through innovative financial program management at the state level by shifting state dollars currently being spent on costly hospital-based cancer care for the benefit of a small number of people to outpatient screening and outpatient-based care for many individuals.
  - Realistically, this type of change cannot happen over night. There would be a transition period during which both types of expenses would be incurred. Therefore, additional funding would be necessary during this transition period to cover the expenses associated with start-up of this new Union County cancer control program. It is anticipated that this investment will come from a combination of private and public sources. The estimate described earlier for outreach and screening of 16,000 at-risk individuals in Union County is \$3.12 million over a four-year period.
- **b)** *Fundraising*. The Union County Cancer Prevention Program should eventually be organized into a non-profit corporation that is permitted to engage in fundraising activities for the purpose of securing donations for use in expanding its cancer prevention program to benefit Union County residents.
- c) Utilize sliding fees for those with the ability to pay for services. The NJCEED Program's income eligibility requirement is income below 250% of the federally defined poverty level. The program currently does not impose fees based on a patient's ability to pay for the services to maximize the number of people screened. However, NJCEED funding (both federal and state) covers screening for only approximately 18% of the state's eligible population for breast and cervical cancer. No federal funding is available for colorectal and prostate cancer screening, further limiting the funding available for screening for these cancers. Other publicly funded health programs currently operating in New Jersey, such as community health centers and family planning clinics, impose fees based on a sliding scale. Those with incomes equal to or less than 100% of the federal poverty level pay nothing for their services, whereas those with incomes in the 250%

range pay full cost for the services they receive. Patients with incomes between 100% and 250% of the federal poverty level pay part of the cost for their services based on a sliding-fee schedule. The imposition of these fees on any patient is governed by an overriding principle that the fees cannot be barriers to receiving the services. Therefore, from time to time, these clinics use discretion in individual circumstances to waive or reduce the fees. This approach to fee collection generates substantial amounts of grant-related income that is used to expand services. To provide additional funds to expand the cancer prevention program, the state should consider employing a sliding-fee scale similar to those that have worked in other public health programs.

#### **Recommendations for State Priorities**

**State Priority 1 – Address funding limitations that are barriers to prevention and care** (AC-4, AC-4.1.6). The need for publicly funded cancer screening services in Union County is substantial. The Union County NJCEED Program provides breast (female), cervical, colorectal, and prostate cancer screening services to the eligible population. However, NJCEED's funding limitation leaves a major gap between the need for publicly supported cancer screening services and the financial resources available to provide these services.

Therefore, despite the efforts of the Union County NJCEED Program, and the availability of other options for cancer screening, a large number of Union County residents who meet the NJCEED eligibility requirements do not receive cancer screening. Taking all these factors into account, it is estimated that approximately 16,000 persons are in need of publicly supported cancer screening services in Union County. Therefore, an increase NJCEED funding for Union County is State Priority #1.

Strategy. Public advocacy campaign for increased state funding of the NJCEED Program.

**Recommendation.** The NJCEED Program should increase funding to cover screening for at least 50% of eligible population. Otherwise the high rates of late-stage cancer and death will continue in Union County and other New Jersey counties with high numbers of medically underserved residents aged 40 years and above.

State Priority 2 – Address Medicaid eligibility issues that are barriers to prevention and care (AC-4, AC-4.1.6). When the diagnosis is cancer, more low-income, uninsured residents of Union County should become eligible for Medicaid automatically regardless of the type of cancer diagnosed or where they were screened and diagnosed. Currently, uninsured, legal, New Jersey residents aged 40 to 64 years with incomes less than 250% of the federal poverty level and a cervical or breast cancer diagnosis are eligible for Medicaid, provided they are screened and diagnosed by the NJCEED Program. Where patients are screened and diagnosed should not matter, according to several key informants. The lack of presumptive Medicaid eligibility for other cancers, such as colorectal and prostate cancer, should also be assessed.

<sup>&</sup>lt;sup>n</sup> As stated earlier, 144,318 county residents (27.6% of the county's total population) are members of clusters that are designated as medically underserved. It is also estimated that 14% of the county's total population is uninsured.<sup>8</sup> Those without health insurance are less likely to receive cancer screening and more likely to have late-stage diagnoses if cancer is found, leading to premature death.<sup>12</sup>

*Strategy.* Public advocacy campaign to change Medicaid eligibility requirements and reimbursements when the diagnosis is cancer.

**Recommendation.** The State of New Jersey needs to expand Medicaid eligibility for cancer patients. Eligibility should be automatic based on the patient's residency, financial status, and diagnosis, not the type of cancer, who does the screening, or where it takes place. Assuming this can be accomplished, the Union County Cancer Prevention Program, as well as other county programs, will have additional funds for cancer prevention and treatment.

State Priority 3 – Address Medicaid reimbursement issues that are barriers to prevention and care (AC-4, AC-4.1.6). Key informants in the region have stated that the state's inability to pay reasonable reimbursement for oncology services needed by uninsured, underinsured, and undocumented individuals is the root cause of the problem of lack of access to care.

*Strategy.* Public advocacy campaign to increase Medicaid reimbursements for oncology services and reimbursements when the diagnosis is cancer.

**Recommendation.** The State of New Jersey needs to increase Medicaid fees for oncology services in order to encourage more physicians – especially oncologists, ENT (ear, nose, and throat) doctors, and gastroenterologists – to participate in the Medicaid Health Maintenance Organizations that serve Union County.

State Priority 4 – Address the use expensive inpatient cancer care services and related reimbursement issues that are barriers to prevention and care (AC-4, AC-4.1.6). Payors, including state-supported charity care, should cover cancer care that can be utilized on an outpatient basis as effectively and safely as on an inpatient basis, such as chemotherapy, pain medication, antibiotics, and home healthcare services.

*Strategy*. Public advocacy campaign to restructure charity care to utilize other lower cost treatment modalities and home care, when appropriate, in order to avoid much higher hospital costs.

**Recommendation.** Charity care should cover outpatient chemotherapy and some medications, especially pain medication and antibiotics, in order to avoid much higher inpatient hospital cost.

# **Closing Remarks**

Despite dramatic advances in detection and treatment, cancer remains the second leading cause of death in New Jersey (surpassed only by heart disease) and in the United States.<sup>2</sup> Cancer has been the leading cause of death among New Jersey adults between the ages of 45 and 64 since 1983.<sup>20</sup> In response to these problems, in July 2002, the Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey published the New Jersey Comprehensive Cancer Control Plan, which has to reduce the burden of cancer for all New Jersey residents as its overarching goal (NJ-CCCP p. xviii).

The Capacity and Needs Assessment provides a detailed baseline assessment for Union County. The data, interpretations, and recommendations were developed to provide a wide array of public health and medical personnel with standardized information and detailed analyses that can help guide and focus their efforts at the county level, including such local health initiatives as the forthcoming Community Health Improvement Plans. The reports from all of the counties will collectively inform the continuing comprehensive cancer control efforts of the Office of Cancer Control and Prevention of the New Jersey Department of Health and Senior Services; the Governor's Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey; and the University of Medicine and Dentistry of New Jersey.

#### References

<sup>&</sup>lt;sup>1</sup> Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey. New Jersey Comprehensive Cancer Control Plan. Report to the Governor, July 2002. i-xx, 1-287. 2002. Trenton, NJ, New Jersey Department of Health and Senior Services.

<sup>&</sup>lt;sup>2</sup> Bullock W, Bock R, Akinosho P. Draft Union County Report, June 2004. In: *New Jersey Statewide County-based Cancer Capacity and Needs Assessment Initiative, 2003–2004*. Editors: Stanley H. Weiss (UMDNJ), Margaret L. Knight (NJDHSS). 2004.

<sup>&</sup>lt;sup>3</sup> U.S. Census Bureau; Census 2000, Summary File 1 (SF 1) 100-Percent Data, generated using American FactFinder, <a href="http://www.factfinder.census.gov/">http://www.factfinder.census.gov/</a>, 2003.

<sup>&</sup>lt;sup>4</sup> U.S. Census Bureau; Census 1990, Summary File 1 (SF 1) 100-Percent Data, generated using American FactFinder, <a href="http://www.factfinder.census.gov/">http://www.factfinder.census.gov/</a>, 2003.

<sup>&</sup>lt;sup>5</sup> U.S. Census Bureau; Census 2000, Summary File 3 (SF 3) Sample Data, generated using American FactFinder, <a href="http://www.factfinder.census.gov/">http://www.factfinder.census.gov/</a>, 2003.

<sup>&</sup>lt;sup>6</sup> Center for Health Statistics, New Jersey Department of Health and Senior Services. County Health Status Profiles, 2000. <a href="http://www.state.nj.us/health/chs/county.htm">http://www.state.nj.us/health/chs/county.htm</a>.

<sup>&</sup>lt;sup>7</sup> Weir HK, Thun MJ, Hankey BF, Ries LAG, Howe HL, Wingo PA, et al. Annual report to the nation on the status of cancer, 1975–2000, featuring the uses of surveillance data for cancer prevention and control. J Natl Cancer Inst 2003;95(17):1276-1299.

<sup>&</sup>lt;sup>8</sup> New Jersey Primary Care Association. County profiles, Union County data report, <a href="https://www.nipca.org">www.nipca.org</a>, October 7, 2003.

<sup>&</sup>lt;sup>9</sup> National Cancer Institute. 2001 cluster profile. Unpublished data. Consumer Health Profile maps of each New Jersey county were provided by the NCI's Atlantic Region Cancer Information Service to NJDHSS/UMDNJ and to each County Evaluator. June 2003. (More information can be obtained from 1-800-4-CANCER.)

Weiss SH, Knight ML. Cancer Resource Database of New Jersey (CRDNJ). 2004. Newark, NJ & Trenton, NJ, UMDNJ & NJDHSS.

<sup>&</sup>lt;sup>11</sup> American Cancer Society, <u>www.cancer.org</u>, September 2004.

<sup>&</sup>lt;sup>12</sup> Committee on the Consequences of Uninsurance, Institute of Medicine, Board on Healthcare Services. Care without coverage: Too little too late. 2002.

<sup>&</sup>lt;sup>13</sup> Center for Health Statistics, New Jersey Department of Health and Human Services. Topics in Health Statistics. Smoking-attributable mortality, New Jersey, 1996–1998. http://www.state.nj.us/health/chs/topics401.pdf.

<sup>&</sup>lt;sup>14</sup> Division of Adult and Community Health, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention. Behavioral Risk Factor Surveillance System Online Prevalence Data, 1995–2003. <a href="http://apps.nccd.cdc.gov/brfss/index.asp">http://apps.nccd.cdc.gov/brfss/index.asp</a>.

<sup>&</sup>lt;sup>15</sup> New Jersey State Cancer Registry, New Jersey Department of Health and Senior Services. Cancer incidence and distribution of stage at diagnosis in New Jersey by county, 1996–2000, for the New Jersey Comprehensive Cancer Control Plan county capacity/needs assessments. Personal communications to SH Weiss. August and September, 2003.

National Cancer Institute and Centers for Disease Control and Prevention. State cancer profiles mortality data. (Continually updated data may be obtained from <a href="http://statecancerprofiles.cancer.gov/">http://statecancerprofiles.cancer.gov/</a>, a site associated with <a href="http://cancercontrolplanet.cancer.gov/">http://cancercontrolplanet.cancer.gov/</a>.) Underlying sources of data: Death data provided by the <a href="National Vital Statistics System">National Vital Statistics System</a> public use data file. Death rates calculated by the National Cancer Institute using <a href="SEER\*Stat">SEER\*Stat</a>. Death rates are age-adjusted to the 2000 U.S. standard population by 5-year age groups. Population counts for denominators are based on Census populations as <a href="modified">modified</a> by NCI. Surveillance, Epidemiology, and End Results (SEER) Program data are explained at <a href="https://www.seer.cancer.gov">www.seer.cancer.gov</a>.

<sup>&</sup>lt;sup>17</sup> Weiss SH, Klotz JB, Rosenblum DM. Estimating prevalence. Unpublished communication. 12/10/2004.

National Cancer Institute and Centers for Disease Control and Prevention. State cancer profiles incidence data. (Continually updated data may be obtained from <a href="http://statecancerprofiles.cancer.gov/">http://statecancerprofiles.cancer.gov/</a>, a site associated with <a href="http://cancercontrolplanet.cancer.gov/">http://cancercontrolplanet.cancer.gov/</a>.) Underlying sources of incidence data: Surveillance, Epidemiology, and End Results (SEER) data, with rates calculated using <a href="mailto:SEER\*Stat">SEER\*Stat</a>. Population counts for denominators are based on Census populations as <a href="mailto:modified">modified</a> by NCI. SEER Program data are explained at <a href="https://www.seer.cancer.gov">www.seer.cancer.gov</a>.

<sup>&</sup>lt;sup>19</sup> Center for Health Statistics, New Jersey Department of Health and Senior Services. Health insurance coverage in New Jersey, 1999–2002. http://www.nj.gov/health/chs/hic9902/hic9902.pdf#Tab5.

<sup>&</sup>lt;sup>20</sup> Center for Health Statistics, New Jersey Department of Health and Senior Services. New Jersey Behavioral Risk Factor Surveillance System: Summary report. Cancer screening among New Jersey adults: 2000–2003.